Health Policy Committee Rep. Kathy Angerer, Chair 124 North Capitol P.O. Box 30014 Lansing, MI 48909-7514

Dear Representative Angerer and Committee Members:

We are writing to you today for two reasons, one to express our appreciation for your consideration of these very important bills HB 5526, HB 5527, HB 5528, and HB5529, and secondly to share our story in the hope that you will understand why such bills are so vital to individuals living with autism. We come to the hearing as well to support this effort and to have you meet our son Nicholas who has autism.

First we'd like to tell you that we are a family of four that have been living with autism since our youngest son Nicholas was diagnosed at age two over fourteen years ago. The day that we heard a pediatric neurologist tell us "Your son has Persuasive Developmental Disorder (autism) and you should really concentrate on your older son because you will most likely have to institutionalize this one" was a day that we will never forget. On the drive home we wept, not knowing what the future would hold, but we also knew as parents of a beautiful young child ~ our precious son, that we could not give up hope.





For many years we were challenged to try to find the best specialists, most appropriate education and services for our son. When Nicholas as three we realized we would have to move to an area which had better overall wrap-around services. At that time both of us were Detroit Police Officers and due to residency requirements we had to resign and leave our jobs to be able to move to Macomb County where educational programs and Community Mental Health Services would better meet the needs of our son. Unfortunately however we found that even with quitting our jobs and moving, we still came to the realization that we would have to provide our son with the interventions he needed to assist him.

We would like you to know that for the past fourteen years we have had double insurance coverage through our respective employers. During that time very little, almost none, of our son's intensive medical and behavioral needs were covered by insurance. Even though our new pediatric neurologist over the years would write us prescriptions for medically sound services such as speech therapy and occupation therapy, these services were not covered. Interventions such as Auditory Integration Therapy, which assisted our son with auditory sensitivity, and well as Sensory Integration Therapy, which assisted our son with tactile defensiveness, were not covered under our very comprehensive insurance policies.

So our journey through interventions, paying for them which have cost us over \$175,000, began in the hope that our son would be able to live a life free of the severe symptoms of autism that would not allow him to speak, made him self-abusive, caused him sleepless nights, and were leaving him out of reach of us as a family. However we continued to have hope, often driving from one therapist an hour away to another therapist an hour away in another direction. We knew however our efforts for Nicholas were important and needed because he began to respond, speak, and become part of our family and his community.





After years of intensive therapies and care from his entire family, Nicholas is now a sophomore in high school and doing very, very well garnering an A in both his general education Science and Drama classes. Though he still is challenged daily by his autism, his triumphs and determination to live to his life to the fullest has been an inspiration to many, especially his family.

We are also sharing Nicholas's story today because of his uncle. Mark Coriaty was diagnosed with Epilepsy at age twelve and lived with chronic seizures the majority of his life. Though he had a genius IQ level, he struggled to live with his disability in an age

when society was not most accepting. Though he was unable to graduate from high school, he had his own business and led a full life until 1999 when he died in Walter Rueter Hospital, where he had been institutionalized, due to lack of appropriate medical care. Mark had a blood clot in his leg from what we believe may have been restraint use while in the hospital. He had expressed for several weeks the pain he was feeling, however this was never medically addressed. He died from pulmonary embolism; the blot clot had traveled to his lungs, at the age of forty four. After his death upon, due to his brain donation to the Autism Tissue Program, it was determined via an evaluation, that he also had been living with Asperger Syndrome, a form of high functioning autism.

Our concerns today, and each and every day, are that our son who we love and cherish deeply could have the same fate as his uncle. He still, even as a sixteen year old young man, is not getting the appropriate medical care he should be entitled to. When taking him to the doctor for medical concerns, many times physician do not provide him appropriate care for immune disorders, intestinal and digestive issues, as well as behavioral interventions. Our live still is a roller coaster as to how he is doing each day and also in wondering what his future will hold.

We do however see the life he is leading and know that he is now living with his autism and it is not identifying him. We as a family have been giving presentations at the Autism Society of America national conferences for the past four years to inspire other parents new to the diagnosis to reach for the stars for their child. But we also have the realization that many of those parents, due to lack of financial resources, may never have their child achieve what Nicholas has been able to. We ask for your consideration in passing these autism insurance reform bills for not only Nicholas, to meet his medical needs as he enters adulthood, but to also meet the needs of so, so many children in this state that can achieve and be more independent and lead fuller lives.





With much appreciation for your consideration of these bills and your efforts to enhance the lives of individuals with autism.

The Gammicchia Family
Andrew, Carolyn, Alexander, and Nicholas